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A Thematic Analysis of Emotional and Psychological Experiences of People with Heart Failure.

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Abstract:	<p>Aims and objectives: To understand the emotional and psychological experiences of heart failure patients in a busy NHS service.</p> <p>Background: People with heart failure often experience depression, anxiety and other emotional and psychological difficulties. Their quality of life is reduced. Qualitative studies attempting to understand this have reported conflicting findings.</p> <p>Design: A mixed methods approach was taken.</p> <p>Methods: Ten participants were asked to complete the PHQ-9 and GAD-7, rate their level of concern about their mood, anxiety, quality of life and social functioning. They completed a semi-structured interview about their experience of living with heart failure and the emotional and psychological impact of this. The interview was analysed thematically.</p> <p>Results: Participants scored in the moderate range on both depression and anxiety measures. They were more concerned about their mood, anxiety, quality of life and social functioning at present compared to before the onset of heart failure. Themes present in the interview data were changes to self and others; emotional reactions; thoughts about death; expectations for the future and hospital experiences.</p> <p>Conclusions: People with heart failure report moderate levels of depression and anxiety, significant changes in their lives and display varying emotional reactions to these. People have clear expectations for the future and impose limits on their life.</p> <p>Relevance to clinical practice: This study contributes depth to the understanding of the psychological and emotional experience of heart failure patients in busy services. Inadvertently it also describes a relatively young sample of heart failure patients and describes good clinical practice.</p>
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A Thematic Analysis of Emotional and Psychological Experiences of People with Heart Failure.

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Abstract

Aims and objectives: To understand the emotional and psychological experiences of heart failure patients in a busy NHS service and make recommendations for how best to support this population.

Background: People with heart failure often experience depression, anxiety and other emotional and psychological difficulties. Their quality of life is reduced. Qualitative studies attempting to understand this have reported conflicting findings.

Design: A qualitative approach was taken with some supporting quantitative data.

Methods: Ten participants were asked to complete the PHQ-9 and GAD-7, rate their level of concern about their mood, anxiety, quality of life and social functioning. They completed a semi-structured interview about their experience of living with heart failure and the emotional and psychological impact of this. The interview was analysed thematically.

Results: Participants scored in the moderate range on both depression and anxiety measures. They were more concerned about their mood, anxiety, quality of life and social functioning at present compared to before the onset of heart failure. Themes present in the interview data were changes to self and others; emotional reactions; thoughts about death; expectations for the future and hospital experiences.

Conclusions: Some people with heart failure report moderate levels of depression and anxiety, significant changes in their lives and display varying emotional reactions to these. People have clear expectations for the future and impose limits on their life. Services can make changes to support this population. Suggestions for doing this are made.

Introduction

Heart failure is characterised by insufficient circulation from the heart, breathlessness, fatigue and water retention. People with heart failure also commonly experience psychological and emotional distress (Bennett et al., 1997, MacMahon and Lip, 2002). Several reviews indicate that people with heart failure report feelings of depression and anxiety (Rutledge et al., 2006, Sokoreli et al., 2015), unsurprisingly given its chronic nature and effect on quality of life.

This study therefore investigates how patients understand their illness and how they experience receiving care from a busy local NHS heart failure service. The aim is to make pragmatic suggestions for how services can support this population's emotional and psychological needs.

Background

How does heart failure affect people?

People living with heart failure experience psychological distress, reduced social functioning and diminished quality of life (Bennett et al., 1997, MacMahon and Lip, 2002), high mortality rates (Cleland et al., 2013), reduced life expectancy (Stewart et al., 2001) and decreased social contact (Murberg and Bru, 2001). The limited research on prevalence of anxiety and depression indicates that levels of both are higher in people with heart failure than in a healthy population. Clinically significant depression is reported by around 21% of the heart failure population when data is pooled, although individual studies ranged from 9%-60% (Rutledge et al., 2006). The authors indicate that the true level is most likely to be around 2-3 times the level reported in the general population. Higher levels of depression are associated with more negative quality of life, even when controlling for other factors (Leftheriotis et al., 2015). Although anxiety in heart failure is still relatively under researched, it appears to be significantly higher than in healthy populations (with around 40% having a diagnosable anxiety disorder) (Moser et al., 2010).

These psychological and emotional difficulties could be understood using the Common-Sense Model (CSM) of illness (Leventhal et al., 1980). The model proposes that an individual constructs a cognitive representation of the illness through a number of factors: illness identity, cause, consequences, timeline. This illness representation is thought to be important in how the individual subsequently behaves in relation to their condition.

A seminal paper by Horowitz et al. (2004) in the USA found that their sample of nineteen patients with heart failure perceived heart failure as an acute disease and therefore did not manage their illness in the manner that a chronic condition is usually managed. They also found that patients had inadequate information about their illness, did not have tools to manage their illness and found barriers in place to receiving care such as lack of knowledge of heart failure cause and symptoms and fears about attending hospital. This study may not be representative of heart failure patients currently in the UK, however, due to cultural differences as well as differing healthcare systems. More recently MacInnes (2014) investigated the experiences

of heart failure patients in South-East England using thematic analysis based on the CSM and found that, in contrast to the findings by Horowitz et al. (2004), people believed that heart failure was a chronic illness with serious consequences. Patients found it difficult to differentiate between symptoms of heart failure, effects of medication and emotional responses to the illness. There was a tendency for people to misattribute heart failure to external factors such as life stresses and family history rather than lifestyle factors. This may affect the patient's ability and motivation to adhere to lifestyle change recommendations such as ceasing smoking and increasing physical activity.

Welstand et al. (2009) reviewed qualitative investigations into the experience of people with heart failure and found five themes that were common to all papers: diagnosis and manifestations of heart failure, perceptions of day-to-day life, coping behaviours, role of others and self-concept. They propose that these concepts have significant overlap and are mediated by the concept of 'self'. They go on to propose that people with heart failure undergo a process of taking on a new identity, a "new self" (p.1380), and need to make sense of this despite "not having a pre-existing script" (p.1383).

Little research attention has been paid to heart failure patients' experience of the psychological and emotional support they receive from busy NHS services. This is important because it is clear this group of people are vulnerable to these issues and the related impact on their quality of life.

Aims

This study aims to understand better how people with heart failure experience receiving care from a busy acute hospital in the South-West of England and to use this information to make suggestions about how similar services could improve the psychological and emotional care they provide.

Method

Design

A qualitative approach was taken with support from questionnaire data. Reported levels of depression and anxiety were analysed quantitatively to allow comparison with the wider heart failure population. Participants completed a semi-structured interview regarding their experience of receiving care from the service.

Ethics

The study was approved by the University of Bath Psychology Ethics Committee (reference 15-220) and the Royal United Hospital NHS Foundation Trust Research and Development department (SE0017) who approved the study as a service evaluation.

Participants

Ten participants took part in this study. Demographic details of participants can be found in table 1. Participants varied in age, ethnicity and severity of illness.

Sampling

A targeted recruitment approach was used to identify people who would be able to describe a breadth of experience. Potential participants were given information about the project by their nurse, and were then contacted by the first author who provided further information, took informed consent and booked an appointment to see them at their home.

Materials

All participants completed a semi-structured interview and two questionnaires:

- The semi-structured interview consisted of seven open questions about their experience of receiving a diagnosis, how they coped with this and the support they received, their expectations about living with heart failure, their predictions for the future and how heart failure has affected them emotionally. They were also asked to rate their mood, anxiety, quality of life and social

functioning (on a 10 point scale) at different time points in relation to their experience of heart failure.

- Patient Health Questionnaire (PHQ-9) (Kroenke et al., 2001) – a widely used 9 item measure of depression symptoms validated in this population (Hammash et al., 2013) . Scores range from 0 to 27 with higher scores indicating more severe depression.
- Generalised Anxiety Disorder (GAD-7) (Spitzer et al., 2006) –a widely used 7 item measure of anxiety symptoms. Scores range from 0 to 21, with higher scores indicating more severe anxiety.

All interviews were conducted by the first author and took 30 to 60 minutes. The interview was audio recorded and transcribed by one of the other authors (CC).

Analyses

The total PHQ-9 and GAD-7 scores were calculated for all participants. Participants' responses to the scaled questions outlined above were collated.

[TABLE 1 HERE]

Qualitative data were analysed using the Braun and Clarke method of thematic analysis (Braun and Clarke, 2006). Each interview transcript was read a minimum of three times or until the first author felt familiar with the content. The first author and the transcriber separately made notes throughout about possible themes and coded the data. Codes were grouped together into preliminary themes which were decided through discussion between authors PS, CD and GMD. These were then refined and checked against the data to ensure they were adequately described.

Results

Quantitative

On average participants scored in the 'moderate' range on measures of depression (PHQ-9 mean 10.6, SD 6.2) and anxiety (GAD-7 mean 8.8, SD 7.9) which is comparable to the general population of people with heart failure (McMahon & Lip, 2002).

On a simple scale of 0-10, participants rated themselves as having more concerns about their mood, anxiety, quality of life and social functioning at present compared to before onset of heart failure. See table two for a summary. No formal statistical analyses were conducted on these data.

The period of illness perceived as the most difficult varied between individuals. This was most frequent around periods in hospital which were often around the time of diagnosis.

[TABLE 2 HERE]

Qualitative

The analysis resulted in five super-ordinate themes: *changes to self and others; emotional reactions; thoughts about death; expectations for the future and hospital experiences*. These super-ordinate themes and their related sub-ordinate themes will be explored further below with supporting quotations

Changes to self and others

Participants discussed how their lives had changed physically, emotionally and relationally, and how these changes affected themselves and others. These changes were both positive and negative. Most frequently people described how heart failure had impacted on their sleep and levels of fatigue. People frequently discussed having to make changes to their sleep routine with many people finding more comfort sleeping upright in armchairs or in uncommon positions.

“I was sleeping sitting down and moving, finding the place where it wouldn’t hurt, and stay like that as I sleep for maybe an hour” P3

Rather than this physical discomfort, however, one participant discussed his worries about not waking up if he fell asleep.

"I just didn't want to go to sleep. I was absolutely knackered and I would just sort of nod off and wake up... It was anxiety about not waking up and just thinking I was going to die" P8

This physical discomfort and fatigue affected participants' ability to carry out both everyday tasks which were important to their role and sense of self and to pleasurable leisure activities. Participants describe a sense of loss of things they previously enjoyed or valued.

"And you know I can't do this, I can't iron now, can't clean, I can't do anything" P7

"I loved hiking. I could do 20 miles a day, no problem, pot-holing, mountain climbing, I loved it all. I can barely climb a fucking curb now." P10

For participant 7 (above) cleaning and ironing were related to her sense of self in terms of her position in her family and culture. To her they signified her role as a mother and wife.

Participants also discussed changes to their social activities. The physical symptoms of heart failure often meant that people declined social events due to expectations of exerting physical energy. This meant that they missed out on potentially enjoyable opportunities to increase their pleasure and self-esteem.

"My friends have invited me over to France a couple of times and I've said that I couldn't manage it, getting in a car, driving over and driving back again and I've said I just can't do it" P9

Heart failure limited participants' ability to work, placing financial pressure on families and affecting their independence. Although most participants discussed negative changes in their life, occasionally people talked about positive changes and how heart failure has allowed them to live a slower pace of life with more enjoyable activities.

"I've had a good life since [the onset of heart failure]. I've been able to do lots of stuff, holidays and this sort of thing. I'm into classic cars and I've [been] buying classic cars and driving them around and what have you." (P1)

Although heart failure is a condition of the individual, it was described as having a significant effect on family and friends. This is possibly related to a change of role or acknowledgment that heart failure may affect the future of the family unit.

"It's interesting because... you know, what happened to me happened to me but it affected my family" P8

"A lot of the time I can't say [about the future] because my husband, I think he battles, I think he battles with it a lot more than I do probably" P6

Acceptance and Avoidance

Participants spoke about coping with these changes in a number of ways generally falling into themes of acceptance or avoidance. Participants frequently used the term 'acceptance' and many gave examples which demonstrated acceptance of their condition, including making the most of life, making positive changes, engaging in appropriate physical activity, internal locus of control and knowing one's limits.

"It's about acceptance isn't it? And dealing with stuff and you can't do everything immediately you just can't. I wouldn't have been able to process stuff and deal with it... you think about all these things but you can't run before you can walk." P8

"The slower you get up to a certain level your fitness will improve up to a certain level but then you get to a certain level and that's it as far as it will go. And all you've got to do to help yourself is make sure you go down to your class to maintain that level you've reached." P1

Some participants did not cope with changes in their life this way. Some people withdrew from their life, compared themselves in unhelpful ways with others, turned to alcohol or smoking, had an external locus of control or used humour or other means to avoid thinking about their difficulties.

"I just stick it to the back of my head and think 'well, don't think about it'" P6

"I start to smoke again, I start drinking again." P3

"There's a man a couple of doors down had a heart attack after me. He's fine, fit as a fiddle. He's running around, he's had his implant put in [but I haven't]" P10

Emotional reactions

Participants described a range of emotional reactions. Most participants described feelings of shock around the time of diagnosis, anger, sadness and fear or worry. Many participants reported emotions changing over the course of their illness, typically from shock at diagnosis to anger at the NHS system and worry about the future and other people.

Diagnosis was typically a difficult time for people, although some reported not reacting particularly strongly as they were unaware what was happening or what heart failure was. Of those who did report an emotional reaction to the diagnosis it was typically one of shock or disbelief.

"When someone says you've got a heart problem it obviously shocks you" P4

"I didn't realise how serious it was...it took me a long time to take in the fact that it was my heart" P5

Many participants reported feelings of sadness. This may have been about their life circumstances or limitations, thoughts about the future or feeling like a burden.

"I'm very sad. I'm very sad." (P7)

Feelings of anger, if present, were usually directed at the hospital system. Frustration was also commonly reported but this was usually in relation to the limitations that were placed on everyday life.

*“As I said, with the doctors and everyone saying, even the consultant saying “it’s urgent, you need to do it, it’s urgent”, why is it taking so f*cking long then?” P10*

Most commonly, participants talked about worry. This was almost exclusively focused around thoughts of their own mortality and the effect of this on their family. This was one of the few themes which was common to every participant and is obviously related to the other theme of ‘thoughts about death’.

“I just hope... if anything... like you say, I just worry about [family]. Are they going to talk to each other? Are they going to open up to each other? Or are they going to sit in their rooms and totally ignore each other all the time?” P6

*“[I’m worried] that it’s gonna f*cking pack in! That’s a big worry! Yes I have worries about it!” P10*

For some participants this worry was accompanied by fear, which was typically a more present-focused emotion specific to a situation. For some participants this was fear around a procedure or of imminent health concerns.

“Whoever you are dealing with I mean they do give you [reassurance] because they know that you’re afraid and you’re frightened” P4

Thoughts about death

This was another theme common to all participants. All participants were aware of their mortality and this was frequently at the forefront of their minds on a daily basis. It possibly underpins some of the positive changes that people have made in their life such as having more open conversations with their friends and family and making changes to their working schedule to allow time for exercise. It also, however, is likely to have been responsible for negative changes such as avoiding pleasurable activities so as not to risk deteriorating their condition. Some people talked about death candidly but some seemed to find it difficult to confront.

"Whenever there's a baby on the way I say 'I don't expect I'll see it' and [my family] all say 'oh don't be daft'. You don't think you are going to live to see another Christmas" P2

"Thinking you are going to die. From today to tomorrow [that is all I am] thinking." P3

"I suppose it brings you up to the frailty of life, you know, and at the end of the day it's a bit of a shock, you know, your life is potentially, is coming to a... you know... we are only here for a given period of time aren't we?" P8

Expectations for the future

Most participants discussed their expectations about what the future will bring as this was somewhat prompted by the question "what do you expect living with heart failure to be like?" The response to this was variable. Some people had a hopeful, but not unrealistic, expectations.

"With my magic box of tricks [pacemaker] fitted I can look forward to a decent future again." P1

"You know, there are a lot of people out there wandering around not knowing [they have heart issues] so I've been through that and got the opportunity for moving on" P8

Some people found the future very difficult to think about. There was a sense of "stuckness" at times. Sometimes the responses people gave may be realistic but the way they were expressed captures a tone of hopelessness.

"There's nothing more they can do. I mean if [I got worse] and I ended up with fluid I don't think they would do anything." P2

"I thought 'my life is gone', you know?" P7

Alongside these responses were participants who were uncertain about the future. This was typically characterised by rhetorical questions like “*what’s going to happen...? Can they do anything...?*” (P4).

Hospital experience

Predominantly participants described the staff they came into contact with as laudable, but the system they worked within could cause upset. In this regard participants talked about the staff as good and the system as bad. It was often the small acts of kindness or care from staff that made the most difference. This could be something as small as providing information at a time when the person was able to receive it, having a conversation about something other than heart failure or just spending time with patients.

“[the nurse] sat there and spoke to you and it seemed as if she had all the time in the world.” P1

“We had chats about football and that included the heart and all the rest of it and she gave you reassurance and everything” P4

“The bickering between [the two hospitals] is about finances and because I’m not from that authority it’s like ‘well, we’ll push that one aside’ and that’s really truly how it’s feeling even though I would not say a bad word about the healthcare team because they are all fantastic; it’s the bureaucrats pushing the pieces of paper around.” P10

Discussion

The aim of this study was to better understand the psychological and emotional experiences and needs of people with heart failure. The participants in this study had heightened levels of depression and anxiety to that reported in healthy populations (comparable to those reported in the heart failure literature) suggesting they were a representative group in this regard. On a measure designed for this study, participants reported heightened current concern about their mood, anxiety, quality of life and social functioning compared to before the onset of heart failure.

Participants described how their lives had changed since the onset of heart failure and how this had been accompanied by a range of emotional reactions and thoughts about the future. All participants had considered their mortality after receiving a diagnosis and some were accepting of their condition and these changes, whereas some were avoidant. This all links with their illness identity, which is a fundamental aspect of the common-sense model of illness perception (Leventhal et al., 1980).

The findings are in agreement with MacInnes (2014), who also qualitatively described a British sample of people with heart failure. She found that participants were clear that their condition was chronic in nature (contrary to Horowitz et al (2004) using an American sample) suggesting that cultural healthcare differences in information-giving or heart failure management may lead to different perceptions of illness. It may also be that understanding of heart failure and related healthcare practices have changed since 2004 when their study was undertaken, and that different results might be found if replicated now. Regarding a chronic illness as such is important in terms of illness management. A mismatch between someone's perception of their illness duration and reality will affect their behaviour, which means that lifestyle, medication management and other factors are also likely to be mismatched. It is important, therefore, to be clear about the chronic nature of heart failure with patients. In the current sample participants were clear that the illness could not be cured although most were aware that it could be managed with appropriate medical intervention. Being aware of this but waiting to receive it was often a source of anger and frustration.

Participants did not report any times which were commonly difficult for them. This suggests that people could be experiencing their most distressing point in their illness at any time, so it is important for health care professionals to keep an open dialogue about how the person is currently feeling in order to capture this. Having said that, a number of people did report that the most difficult periods were around diagnosis, initial hospitalisation, and also a number of weeks afterwards, so particular focus could be given to these times. This may be around the time that people are looking toward discharge, adjusting to life in recovery, and facing changes in their lives to come. Participants also discussed the impact of heart

failure on their relatives given the potential impact that a diagnosis may have on their own lives and emotional wellbeing. This is in keeping with findings that caring for someone with heart failure can affect physical and psychological health (Pattenden et al., 2007).

Participants clearly reported that clinical staff were supportive and caring. They often had strong views about the healthcare system and delays in receiving interventions. With that in mind it is possible to make recommendations which can be integrated into routine clinical practice and do not require further resources or time. By amending current practice to reflect the insight given by our participants the impact of having a diagnosis on patients and their families could be reduced. These include:

- Clinical staff are well placed to advise patients on how their lives could be adapted so not to limit their lives unnecessarily. It may be that patients can adapt their level of intensity, spread an activity over a longer duration or split an activity into smaller, manageable chunks. This could happen during routine check-ups using motivational interviewing techniques and resources (see Rollnick et al., 2009 for a guide on using motivational interviewing in health care).
- Clinicians should be aware of the impact of the diagnosis on family members as well as the patient. Consider having ongoing open discussions with both parties about the condition and expectations for the future. The worst point in the illness is variable, so it is important that this is continued after diagnosis.
- The patients appreciate being given time and having non-heart failure conversation as well as being given relevant information. These moments of non-heart failure conversation were important in the development of a relationship and significantly improved the experience of the patient. Increasing these where possible would be beneficial.
- Patients inevitably think about death and many have the view that their life is over. They could be further supported to explore activities they are still able to engage in which could maintain their quality of life. Openly discussing thoughts and beliefs about death during consultations could help patients

understand they are not alone in thinking about this and normalise a potentially distressing experience.

- Patients may have difficulty remembering the advice and support given during their inpatient stay so written information may be particularly useful and they may benefit from information about the emotional impact of receiving a diagnosis of heart failure. There are several information booklets available online or the service may wish to produce a specific booklet for their needs.

Although a service can always make improvements it is important to recognise the model of good clinical practice this service achieves. The patients generally felt well supported and spoke highly of their heart failure nurse. Patients seemed to perceive the support they received as personal and it was the small acts of kindness which improved their stay. These could be adopted or encouraged by any service, even where no specialist nurse is available.

Limitations

Although qualitative analysis will not provide generalisable answers, it does offer a rich account of the experiences of heart failure patients in this service in the South-West of England. It seems plausible that the recommendations made here could be applied to other heart services in the UK or further afield. Larger scale quantitative research would offer more insight into this.

Conclusions

This study aimed to describe the psychological and emotional needs of a heart failure population to make recommendations for care within a busy NHS service in South-West England. Participants reported moderate levels of depression and anxiety. Themes present in the data include changes to self and other, emotional reactions, thoughts about death, expectations for the future and hospital experiences. A number of small changes for clinical practice could be implemented to improve the experience and emotional wellbeing of patients.

Key points

- People with heart failure experience a range of emotional and psychological issues and carry a significant burden of disease.
- When given an opportunity to reflect on their care, patients from busy hospitals have a wide variety of emotional and psychological experiences and speak most positively of the human interactions such as a short conversation about something other than their condition.
- Most patients consider their own mortality when diagnosed with a serious condition. Talking about this is not to be avoided.
- The diagnosis of heart failure has a significant impact on family and loved ones as well as the patient and can affect relationships.
- Clinicians running heart failure services are well equipped to manage these difficulties.

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Table 1: Demographic data and responses to questionnaires.

Participant number	Gender	Age	PHQ-9	GAD-7	NYHA	Number of Admissions
1	M	68	2	1	2	2
2	F	74	19	7	3	>10
3	M	72	15	21	3	1
4	F	51	4	4	2	1
5	M	66	5	0	3	2
6	F	74	20	16	3	3
7	F	47	13	21	2	4
8	M	56	8	9	2	1
9	M	75	12	3	2	>10
10	M	51	8	6	2	3

*New York Heart Association Functional Classification – larger number represents more severity.

Cut offs: PHQ-9 - 5 (mild), 10 (moderate), 15 (moderately severe), 20 (severe); GAD-7 - 5 (mild), 10 (moderate), 15 (severe)

Table 2: Scores on quantitative interview questions. Participants rated their concern in these areas out of ten.

	Mood			Anxiety			Quality of Life			Social Functioning		
	<i>Pre</i>	<i>Worst</i>	<i>Now</i>	<i>Pre</i>	<i>Worst</i>	<i>Now</i>	<i>Pre</i>	<i>Worst</i>	<i>Now</i>	<i>Pre</i>	<i>Worst</i>	<i>Now</i>
Avg.	0.5	5.9	4.0	2.0	5.6	4.1	1.1	4.3	4.6	2.2	4.6	4.5